THE PERCEPTIONS OF PREGNANT WOMEN ATTENDING ANTENATAL CLINICS IN QWA-QWA, FREE STATE, SOUTH AFRICA, REGARDING THE PMTCT PROGRAM

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To the academic staff of the University of Stellenbosch:
The members of the committee appointed to examine the thesis of
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DECLARATION

I, VICTOR AIMUAGBONRIE AKEKE hereby declare that the work on which this dissertation is based, is original and that neither the whole work nor part of it has been, or shall be submitted for another degree at this or any other university, institution for tertiary education or examining body.

VICTOR A. AKEKE

GLOSSARY

AIDS	**Acquired Immune Deficiency Syndrome**
ANC	**Ante Natal Care**
ART	**Antiretroviral Therapy**
ARV	**Antiretroviral (Drugs)**
AZT	**Zidovudine**
HAART	**Highly Active Antiretroviral Therapy**
HIV	**Human Immunodeficiency Virus**
ILO	**International Labour Organization**
MCH	**Maternal and Child Health**
MDG	**Millennium Development Goals**
MTCT	**Mother-to-Child Transmission**
NGO	**Non- Governmental Organization**
NVP	**Nevirapine**
PLWHA	**People Living with HIV/AIDS**
PMTCT	**Prevention of Mother-to-Child Transmission**
VCT	**Voluntary Counselling and Testing**
WHO	**World Health Organization**

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ABSTRACT

Background: The prevalence of cases of HIV among children below the ages of 15 years continues to increase and majority of these children acquired the infection through mother-to-child transmission.

Methodology: The main objectives of the study were to explore the perceptions of local women regarding the PMTCT program, to evaluate the strength of these perceptions and to make recommendations. A qualitative method was used involving a number of focus group discussions among antenatal clinic attendees in the 27 primary health care clinics in Qwa-Qwa, Free State province of South Africa.

Findings: The findings were organised under eight major themes: (1) Knowledge of the program -where the participants expressed high knowledge about the PMTCT program as they knew how MTCT of HIV occurs and how it can be prevented, (2) Perceived concerns about the program- which were mainly fear of resistance to ARVs, fear of stopping the treatment after delivery, potential for high numbers of orphans, depression and suicide when HIV result is positive, the fear of the family neglecting the baby if the mothers dies, the perception that the program cares for only the babies and not their mother, (3)Readiness to do HIV test- where majority of the participants said it was difficult doing the HIV test due to fear of positive result, (4) Ease of taking ARVs- Difficulty in taking the ARVs due to fear of resistance and harmful side effects, (5) Relationship with clinic staff- a majority of the participants were happy with their relationship with the clinic staff, (6) Reactions expected from family members when program advice is followed- more than half of the participants expected negative reactions from family members if the program advice is followed because of the negative attitudes of their male partners and the elders' of the resistance to change from their cultural beliefs, (7) Advantages of the program- according to the focus group participants, the advantages of the program include the knowledge gained about HIV, modes of MTCT of HIV and how to prevent MTCT of HIV. Other advantages mentioned were prevention of MTCT of HIV, pre-test counselling reducing the fear of doing HIV test, knowing one's HIV status as well as the potential of the program to have positive change on the cultural beliefs of the people, and lastly (8)How they felt being part of the program- where all the participants said they were excited .

Conclusions: The findings were similar to those of other studies in many respects.

Recommendations: The recommendations were community and family HIV/AIDS education and their involvement in the PMTCT program in other to reduce misconceptions about the disease, and stigmatization against the women in the program. Other recommendations include: the concept of PMTCT-plus which provides ongoing support and treatment for the mothers, babies and infected family members**;** integration of innovative health education and culturally appropriate interventions into the program**;** provision of adequate maternity leaves to women in the PMTCT program as well as full integration of the PMTCT program into the District Health System (DHS) as part of the "horizontal" delivered package.

CHAPTER ONE

INTRODUCTION

1.10 BACKGROUND

The prevalence of cases of HIV among children below the age of 15 years continues to increase, especially in the countries hardest hit by the AIDS epidemic. The majority of infected children acquire the infection through mother-to-child transmission.[1]
As a result of this, the prevention of HIV infection in infants and young children is now more important than ever before.

Although HIV infection among infants is a problem all over the world, it is worst in Sub-Sahara Africa where almost 90% of all HIV infected children live.

The rates of mother-to-child transmission vary from 15% to 30% in the absence of any intervention, and without breastfeeding.[2]A further 5-20% will become infected with HIV through breastfeeding.[3]

Several short courses of antiretroviral regimes have reduced transmission rates to about 10%. The regime widely used in developing countries is the single dose Nevirapine to the mother and baby (HIVNET 12).[4]

The risk of resistance can be reduced if a combination regime (dual therapy) of Zidovudine (AZT) from 28 weeks of pregnancy, in addition to the peri partum Nevirapine (NVP) doses given to mother and baby is provided.[5]

1.20 PMTCT Services in South Africa

South Africa is one of the countries that have the highest rates of HIV infection with sero-positive rates of 30% in antenatal clinics in some provinces including the Free State province. In the absence of the PMTCT program, it was established that about 50,000 infected babies were born each year in the country. Extrapolations of the 2005 annual antenatal HIV sero-positive survey estimate that there are 235,000 HIV infected children less than 15 years of age in South Africa.[6] However community-based surveys generally identify higher childhood sero-prevalence rates, for example, the 2002 Human Sciences Research Council (HSRC) study showed that 5.6% of children aged 2-14 years were HIV- positive.[7]

Following a High Court ruling initiated by the Treatment Action Campaign (TAC), the South African government decided to roll out the use of Nevirapine in the prevention of mother-to-child transmission of HIV (PMTCT) in 2002. Initially 18 pilot sites were set up (2 pilot sites in each province), and this was later scaled up to be implemented in all public health institutions.

1.30 Brief Description of Health Services in Qwa-Qwa

This study was conducted in the Primary Health Care clinics of Qwa-Qwa. Qwa-Qwa is a rural town in the eastern part of the Free State in South Africa. The population served is a predominantly black/Sesotho speaking community of about 300,000 people. The community is served by one regional (or level 2) hospital and one district (or level 1) hospital. There are 28 Primary Health Care clinics that refer patients to the district hospital. The pregnant women attending these clinics for their antenatal care (except those attending the clinic in a small town called Kestel which is about 30km from Qwa-Qwa) were interviewed during the course of this study.

Although, the dual therapy which is the addition of Zidovudine (AZT) to Nevirapine (NVP) was approved by the Free State province in May 2008, the implementation of the guideline at the primary health care facilities started only in December that year. With this new guideline, the AZT is started at 28 weeks of pregnancy in addition to the single dose peri partum NVP given to mother and baby. Before December 2008, only single dose NVP was provided.

1.40 Problem Statement

In the district hospital maternity ward, it is common to see women from the PMTCT program coming to the hospital during labour without their Nevirapine tablets. At the same time, the number of children under 12 years of age with HIV-related illnesses coming to the Paediatric wards of the hospitals in Qwa-Qwa is on the increase.

To date, the PMTCT program has been facing many challenges, which relate to staff shortages, poor infrastructure, unavailability of equipment, and negative community attitudes.

It has been reported that some communities have misconceptions regarding the PMTCT program. This study is an enquiry into what the women attending antenatal clinics in Qwa-Qwa think or feel about the PMTCT program.

The study explored the perceptions of the pregnant women on the PMTCT program and the information gained from this study may help to modify the PMTCT program locally as well as in similar contexts elsewhere.

CHAPTER TWO

LITERATURE REVIEW

2.10 Mother to child transmission of HIV overview

As already stated in the introduction chapter, the rates of mother-to-child transmission vary from 15% to 30% in the absence of any intervention, and without breastfeeding, while a further 5-20% will become infected with HIV through breastfeeding.[2, 3]

In 2005, it was estimated that about 700,000 children under the age of 15 globally become infected with HIV mainly through mother-to-child transmission. About 90% of these MTCT infection occurred in Africa.[2]

Mother-to-child transmission of HIV can occur during pregnancy, labour and delivery, or breastfeeding.

To effectively prevent mother-to-child transmission (PMTCT) of HIV, a four-pronged strategy is required.[8, 9, 10] These are: primary prevention of HIV among women and their partners; avoidance of unwanted pregnancies among HIV positive women; prevention of HIV transmission from HIV positive mothers to their babies (PMTCT) during pregnancy, labour, delivery and breastfeeding and provision of treatment, care, and support to HIV positive women, their children and families.

Interventions for the prevention of mother-to-child transmission of HIV during pregnancy, labour, delivery, and breastfeeding include the use of antiretroviral drugs, replacement feeding from birth, elective caesarean sections and minimizing the practice of invasive obstetric procedures like episiotomy, artificial rupture of membranes and foetal scalp monitoring in HIV infected women.[9, 10]

2.20 Women's perceptions as a barrier to PMTCT program implementation

Socio-cultural practices could hinder the implementation of prevention of mother-to-child transmission of HIV especially in rural areas.

One study, was conducted in a rural South African setting, [11] used qualitative methods to examine how socio-cultural factors would affect adolescent mothers' ability to adhere to PMTCT programmatic recommendations. The aim of the study was to know how mothers' decisions affected PMTCT related practices and to identify contextual factors that impacted on their resolve and actions. It was found that rural adolescents are less likely than their urban counterparts to implement most PMTCT- related practices as a result of HIV stigma, family decision making and cultural norms surrounding infant feeding. Also noted were barriers to behaviour change in areas such as history, culture, gender and power.

A similar study was conducted in rural and urban Uganda, [12] which examined the potential barriers that might affect the acceptability of interventions for PMTCT in rural and urban settings. It was a cross-sectional survey conducted over a period of 4 months. Four hundred and four mothers attending antenatal clinics in rural and urban parts of a district in South West Uganda were interviewed face to face. It was revealed that the level of knowledge of MTCT and rapid HIV testing were equally high in both areas but the women from rural areas had a higher tendency to think that they should consult their husbands before testing (72% vs. 64% p=0.09). Health facility-based deliveries were also lower amongst mothers in rural areas compared to those of urban setting. Important predictors of willingness to test for HIV were post-primary education (OR = 3.1 95% CI 1.2, 7.7) and knowledge about rapid HIV tests (OR = 1.8, 95% CI 1.01, 3.4). However, the strongest predictor of willingness to test for HIV was the woman's perception that her husband would approve. The women who thought their husbands would approve were almost six times more likely to report a willingness to be tested compared to those who thought their husband would not approve (OR= 5.6, 95% CI 2.8, 11.2). The women, however, were not followed up after the survey to determine who eventually accepted HIV testing. The authors concluded that the lessons learnt in urban areas could be generalized to rural settings, and that same-day results are likely to ensure high uptake of HIV testing, but the involvement of the male spouse should be considered, especially in rural settings. Universal primary education will also support the success of the PMTCT program.

Another study in Burkina Faso revealed that communication with partners plays a vital role in the uptake of HIV testing. With the main objective of analyzing the factors associated with uptake of HIV counselling, HIV testing, and returning for test results in a rural hospital setting, a cross-sectional survey of 435 pregnant women who visited the district hospital for antenatal care was conducted between July and December, 2004. Separate multivariate logistic regression analyses were performed to identify the factors associated with accepting HIV counselling and testing. The results showed that participation in HIV testing was related to discussing HIV screening with partners (OR 8.36), and the number of antenatal visits the patients had recorded before the test.[13]

2.30 Perceptions on infant feeding

Replacement feeding is not usually acceptable by most women as they think it is against societal norms.

In an ethno-graphic research conducted in eleven low-resource settings in South Africa, Namibia and Swaziland with the aim of understanding how the perceptions and experiences of counselling health workers, pregnant women and recent mothers could be used to improve infant feeding counselling, it was discovered that very early mixed-feeding remains usual practice despite the PMTCT program. The traditional belief of "water as life" and "milk as fluid" were militating against the current PMTCT education, as milk is considered to be a liquid 'drink' rather than 'real food'.[14] This perception

worsens the "insufficient milk syndrome" where disempowered mothers perceived themselves and their breast milk as deficient- 'not good enough'.

Another study evaluated infant feeding practices in PMTCT and non-PMTCT sites in Botswana.[15] The Botswana Food and Nutrition Unit, in collaboration with UNICEF undertook this study with the aim of generating baseline information and to evaluate feeding practices and their determinants; mothers' program perceptions and service utilization; health worker knowledge, attitudes and practice, as there had been a concern over replacement feeding with regard to quality of counselling, mothers' support and actual practices. It was a cross-sectional study that showed 89% of the HIV-positive mothers formula-fed exclusively. Among the HIV- infected mothers who were breastfeeding, 20% practiced exclusive breastfeeding. Breastfeeding HIV-infected mothers received little advice on safe transition to other feeds. Exclusive breastfeeding rates were much lower in the PMTCT sites mainly as a result of early introduction of formula feeds. Health workers' knowledge of infant feeding was poor. The author concluded that there is urgent need of training for service providers, counselling and support for women opting for breastfeed. However, the author warned that caution should be exercised before extrapolating some of these results to other countries.

In Abidjan, Cote d'Ivoire, research was conducted to assess the social impact and perceptions of women after a two-year follow-up in a PMTCT project.[16] Women who were diagnosed with HIV-1 infection were included in the study during their third trimester of pregnancy. PMTCT interventions were proposed. Seventy-seven women who reached the end of the follow-up between May and December 2003 were systemically interviewed. The results showed that the family structure had changed for 33 women since inclusion in the study, out of these, 6% linked their reasons to the project i.e. sero-status disclosure, infant feeding intervention and too frequent visits to the clinics. 43% disclosed their status to their partners and 57% informed them of their participation in the project. Among the women who choose to participate in formula feeding from birth (N = 48), 37% of them reported difficulties in feeding their baby since their partner (17%) or their family (83%) disagreed with their practice. Among those who practiced breastfeeding, but with early cessation or drop-out (N = 29), 21% explained the reasons of their practice to their partners, 54% reported support of their family, while 36% faced opposition and 55% were ready to do it again. 12% regretted accepting HIV screening during pregnancy while 82% would recommend HIV testing to a pregnant friend. In conclusion most of the women who tested positive had a positive opinion of their 2-year participation in the project despite the difficulties reported and would be ready to do it again. Alternatives to breastfeeding created social difficulties for the mothers, which should be taken into account in the evaluation of these interventions.

2.40 Community perceptions of PMTCT Program

Some work has been done to explore the challenges and perceptions of communities in Africa on the PMTCT program and many of these perceptions have the potential to impact negatively on the implementation of the program.

UNICEF has assisted countries in developing PMTCT communication strategies, since May 2000, with the aim of increasing community involvement in developing solutions to support HIV affected families, reduce stigma and discrimination.[17] Community dialogue in many PMTCT program areas revealed very useful lessons. The author summed up the findings as follows:

"*The "M" in PMTCT can foster an incorrect perception that a woman is at fault in infecting her baby hence, men and extended families often do not feel responsible for caring for infected women and children. In some areas the community chases away known HIV infected people, including women and children. Community assumption of female promiscuity due to HIV positive status makes it impossible for so many women to remain in their community where they might have access to better home - based care, pushing them into urban poverty and often into sex work to earn a wage. Fear of abandonment has led to a heightened degree of secrecy and lack of trust between partners, leading to reduced disclosure of HIV status between men and women. Communities are often overwhelmed with HIV/AIDS issues and have difficulty in identifying ways in which they can better support HIV infected families*"

The author recommended that more deliberate and concentrated efforts should be made to look at HIV/AIDS holistically as a societal issue, in order to increase the awareness and understanding of basic knowledge of HIV/AIDS such as transmission and prevention; and to place strong emphasis on understanding and addressing community beliefs, cultural practices and norms related to HIV/AIDS, illness, pregnancy, infant feeding and relationships. The author also recommended the "use of community dialogue tools to assist communities in identifying realistic locally-appropriate ways to create more caring and supportive environments for HIV-affected families".[17]

In another study, community perceptions were explored at PMTCT sites in Hai and Kilombero districts of Tanzanian.[18] Four focus groups of pregnant women were conducted, 2 with married men and 2 with influencers (women over 45 with grand children) in each district. It was found that while most respondents knew about HIV, some expressed fear to accept VCT due to stigma and because HIV is incurable. One third of the study participants in one of the districts expressed the hopelessness of saving the baby when the mother and husband are going to die- "why should I die and leave my child to suffer?" Some participants mentioned taboos like taking water during labour, which is believed to inhibit uterine contractions, and which has implications for the swallowing of Nevirapine. Also there is a belief that a new born should not see the sun before 40 days after birth, which implied that HIV positive mothers may not take their infants to the facility for their Nevirapine syrup. The authors recommended that these perceptions should be taken into account when designing the PMTCT program and communication messages should be developed to counter myths and dispel concerns.

Some communities do not know that vertical transmission from mother to child is one of the routes of HIV transmission. A community based study describing opinion leaders' awareness and perception of PMTCT services was carried out in Ibadan, Nigeria.[19] It was a qualitative study, where in-depth interviews were conducted by trained interviewers

using a pre-tested interview guide. Twenty [12 (60%) males and 8 (40%) females] participants aged between 40 and 65years were selected as opinion leaders to take part in the study. The results showed that even though general awareness of HIV/AIDS was high, their level of awareness and knowledge regarding mother-to-child transmission was low. None of the participants mentioned mother-to-child transmission as the route of HIV transmission until they were prompted. The participants described mother-to-child transmission of HIV as a transmission that occurs through mother and child sharing sharp objects, through breastfeeding and in the womb. One participant was not happy to accept VCT for pregnant women, because if it turns out to be positive it will affect the health of the women. Half (50%) of the women were aware of the availability of PMTCT services and where the services are rendered, but no one knew of anybody utilizing the services. The author concluded that there is a need for strong advocacy, enlightenment and community mobilization for improving awareness and utilization of PMTCT services.

2.50 Gender Inequality and Vulnerability of women to HIV/AIDS

Worldwide, women constitute half of all people living with HIV/AIDS.[20] And globally and in every region, more adult women (15years or older) than ever before are living with HIV.[21]

Women are at least twice more likely to acquire HIV from men during sexual intercourse than vice versa.

In sub Sahara Africa, women constitute 61% of all people living with HIV/AIDS. Among young people aged 15-24, the HIV prevalent rate for young women is almost three times higher than the rate among young men.[21]

Women and girls experience specific challenges in the face of high HIV rates as a result of cultural norms and practices which reinforce their disadvantaged economic position and social status.[22]
The former United Nation Secretary-General, Kofi Annan in 2004, reiterated the plight of women in the face of HIV/AIDS in his message on the International Women's Day which was observed on the 8th of March, 2004. According to Kofi Annan, a vicious cycle develops as AIDS strikes at the lifeline of society that women represent. Poor women are becoming even less economically secure as a result of AIDS, often deprived of rights to housing, property or inheritance or even adequate health services. In rural areas, AIDS has caused the collapse of coping mechanisms that for centuries have helped women to feed their families during times of drought and famine, leading in turn to family break-ups, migration, and yet greater risk for HIV infection. As AIDS forces girls to drop out of school—whether they are forced to take care of a sick relative, run the household, and help support the family – they fall deeper into poverty. Their own children in turn are less likely to attend school—and more likely to become infected. Thus, society pays many times over the deadly price of the impact on women of AIDS.[23]

Women are usually not the ones with most sexual partners outside marriage, or more likely than men to be injecting drug users but are more vulnerable to HIV infection because society's inequality puts them at risk. Many factors such as poverty, abuse and violence, lack of information, coercion by older men, and men having several partners increases women vulnerability to HIV infection. That is why many mainstreaming prevention strategies, for example those based exclusively on the 'ABC' approach—"abstain, be faithful, use a condom" are untenable. Where sexual violence is widespread, abstinence or insisting on condom use is not a realistic option for women and girls. Nor does marriage always provide the answer. In many parts of the developing world, the majority of women will be married by age 20, and have higher rates of HIV than their unmarried, sexually active peers mainly because their husbands have several partners.[23]

Between 1998 and 2001, an advocacy-research project was carried out by the International Community of women living with HIV/AIDS with the main objective of exploring the impacts of HIV/AIDS on women's sexual and reproductive lives, the research showed that married women were at risk of contracting HIV due to their husbands' infidelity.[24]

In South Africa, men are generally expected to have multiple partners, while women are expected to have high fertility, which is highly constituent to women's self-perception as the women's status depends on their ability to have children.[25] (Rutenberg et al, 2003). This is one of the reasons for the HIV/AIDS epidemic in the country and according to Willan, HIV/AIDS epidemic is reversing the legal gender equality achievements that have been recognised by South African Constitution as women and girls have become the caregivers, the "hospice workers", the "social workers", the "foster parents"- with no pay, no recognition, no future- and have a greater likelihood of being infected with HIV/AIDS than their male counterparts (Willan 2002).[26]

The health section of the Beijing Platform of Action which was adopted in 1995, among other things states that the empowerment and autonomy of women and the improvement of their political, social, economic and health status is a highly important end in itself, and essential for the achievement of sustainable development.[27]

Also recognising gender equality is the Millennium Development Goals (MDG) elaborated by world leaders in 2000, where critical areas identified at major UN conferences were summarised and the goal number 3 is 'To promote gender equality and empower women'.[28]

According to Article 14 of the Declaration of Commitment from the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS." [29]

2.60 Women Empowerment and the PMTCT Program

Most PMTCT services are organised with the assumption that women are free to act independently, and have the resources to access testing, counselling, and pre- and post natal care, and breastfeeding alternatives. This is wrong as women are faced with many gender-based obstacles to preventing mother-to-child transmission of HIV/AIDS.

Women's economic dependency increases their vulnerability to HIV and this economic vulnerability of women makes it more likely that they will exchange sex for money or favours, less likely that they will succeed in negotiating protection, and less likely that they will leave a relationship that they perceived to be risky.[30, 31, 32] Also, women economic dependency may make the women to be unable to access pre-natal health services as their partners controls the household financial or transportation resources, or because they can not take time off work or leave dependents to travel to a clinic or hospital.
HIV positive women may be unable to negotiate sex or contraceptive use, or to access contraceptives which can lead to unplanned pregnancies.

Also, because of fear of rejection, stigmatisation and violence or abuse, women may not use HIV voluntary Counselling and testing services, disclose their HIV status, access PMTCT services or engage in alternative infant feeding practices.[33]
Empowerment does not refer only to "power over" resources, institutions and decisions making, but also consist of being able to control discussions, discourses and agendas.[34]

There is a possibility that ethical complication may arise in the PMTCT program framework as some of the services seem to focus mainly on the health of the child. ARVs are often withdrawn after the woman has given birth to the baby. This may give the impression that the program is only meant to prevent transmission of HIV to the child.[35] The psychological, economic and social consequences for the woman for being aware of her sero-status could be very overwhelming and traumatizing in many settings. As a result the advantages of knowing her status such as enrolment in a PMTCT program to reduce the risk of the infant getting the virus from her, could be outweighed by the disadvantages such as persecution and violence for the woman, hence there is ethical dilemma of whose rights should be prioritized, the mother's or the child's.[36]

CHAPTER THREE

METHODOLOGY

3.10 Aim and Objectives

Aim

The aim of this study was to assess the perceptions of women attending the antenatal clinics in Qwa-Qwa concerning the PMTCT program.

Objectives

The objectives were as follows:

1. To explore the perceptions of local women regarding the PMTCT program.
2. To evaluate the strength of these perceptions amongst women regarding the PMTCT program.
3. To make recommendations as to how the PMTCT program can better respond to or anticipate the perceptions of women.

3.11 Study Design

As the aim of the study is to explore the perceptions of these women (i.e. their beliefs and feelings about the PMTCT program) a qualitative methodology, involving a number of focus group discussions was used.

3.12 The Study Population

The target population for this study were the pregnant women attending Antenatal Clinics in Qwa-Qwa. There are 27 Primary Health Care clinics offering antenatal care services in Qwa-Qwa (the 28^{th} clinic is in Kestel, a small town that is about 30km from Qwa-Qwa and was not included it in this study). These 27 clinics were grouped into 4 clusters according to the catchments areas. A focus group discussion was held in each of these clusters. Each focus group consisted of 8-11 women where at least one woman represented each clinic; about 39 subjects participated in the study. The pattern of antenatal visits in these 27 clinics from the months of January 2008 to March 2008 is attached as an **Appendix**.

In addition to the above, the following inclusion and exclusion criteria were applied:

3.13 Inclusion and Exclusion Criteria

Inclusion Criteria

1. All women interviewed were 18 years old and above (i.e. above the age of consent) irrespective of the number of antenatal visits recorded or the gestational age of their pregnancies.

2. They were attending Antenatal Care in the designated clinics at the time of the study.
3. The women had pre- and post-test HIV counselling.
4. Those who tested negative or positive for HIV as well as those who refused testing were included in the study (the idea was to see if their perceptions will differ).
5. Women of all races and background were included in the study.

Exclusion Criterion

1. Refusal to participate or sign the consent form.

3.14 Data Collection

The data were collected using four focus group discussions which explored the perceptions of the women regarding the PMTCT program.

The open ended questions that guided the focus group discussions were as follows:

Opening question
What do pregnant mothers in this area think about the program at the clinic to prevent transmission of HIV to their babies?

Middle questions
What do you know about how HIV is passed from mother to child?
What do you know about how the clinic tries to prevent this?
How easy is it for mothers to agree to the HIV test?
How easy is it for mothers to take the Nevirapine?
What are the main concerns that pregnant mothers have about the program?
What does it feel like to be part of the program at the clinic?
What is the relationship like between the mothers and the clinic staff?
If you follow the program's advice what reaction do you expect from your family?

Closing question
What from your point of view are the pros and cons of the program?

3.15 How the participants were approached and recruited

The nursing sisters in the clinics assisted in the recruitment of the participants since it was very difficult to go the 27 clinics now and then to approach the patients personally.

The nursing sisters were informed about the project. They in turn informed the ante natal clinic patients in the patient waiting areas, during consultation and during the pre test HIV counselling sessions with the aid of the patient information leaflet which had already been translated into Sesotho language. Interested patients were then recruited by the nurses in each of the designated clinic who then send me the list of those recruited.

3.16 Procedure

Four focus group discussions were held. Clinics with accommodation facilities were selected as the venue for discussion in each of the cluster area, and the participants in that cluster area met in that clinic on a particular date and time for the discussion.

Each focus group comprised of about 8 to 11 participants. A total of 39 pregnant women participated in the focus group discussion in the 4 cluster areas.

Consent forms were signed by all participants at the beginning of the discussion sessions. During the discussions, the participants were encouraged to feel free to express themselves and to be opened in their discussions concerning their experiences, ideas and beliefs regarding the PMTCT program.

A focus group discussion guide in the form of open-ended questions as shown above in the data collection section was used in order to ensure that important issues were not left out.

An interpreter was recruited to translate from Sesotho to English language and English to Sesotho language as Sesotho is the major language spoken by the inhabitants of Qwa-Qwa.

The sessions were approximately one and a half to two hours in length and the discussions were recorded with a cassette tape recorder as well as by writing field notes.

English language transcripts of the discussions were made directly from the audiotapes and were analysed thereafter.

3.17 Method of data analysis

A four-stage approach was used for the data analysis. [37]

- First was the familiarization stage where I immersed myself in and get to know the data.
- The second stage was the indexing of the data. At this stage, key themes were identified and an index was then created so as to make it easier to code each data segment.
- The third stage was the grouping of the data. This was where data segments from different interviews that shared the same thematic elements were grouped together on a chart or sheet of paper.
- The last or the fourth stage was the interpretation of the thematically charted qualitative data. Here, the data were worked on to explore themes and make interpretations.

3.18 How findings will be given back to the community involved

The findings of the project will be presented in one of the district clinical meetings usually attended by the nurses from the clinics, representatives of the Emergency Medical Services (EMS), rehabilitation team, doctors, medical superintendents, nursing managers and hospital Chief Executive Officers (CEO).

In addition, the findings will be summarised and leaflets containing these summaries will be sent to the clinics and area managers' offices where they will be displayed in conspicuous places in these clinics and offices.

3.19 Ethical Considerations

How the pertinent ethical issues were managed

The outcome of this study will hopefully in future benefit the pregnant women on PMTCT program as the information acquired will help to improve the design and implementation of the program.

All ethical standards pertaining to human research have been carefully considered in this study.

Competent medical personnel including myself were involved in this project. The non-medical personnel that were used during the interviews and data collections (i.e. field workers) were trained to be able to perform their duties successfully.

The potential risks were that some participants might become emotionally distressed during the focus group discussion and it was planned that a psychologist would attend to that participant should such happen, but fortunately such incident did not occur. Also, information of personal or sensitive nature was divulged during the sessions

The confidentiality of the respondents was maintained. No names were recorded as part of the personal data. The right to privacy was protected by the use of codes instead of names during the focus group discussions. The participants were told not to introduce themselves before responding to the questions asked. All these helped to reduce stigmatization during the focus group discussions.

Participation in the study by the subjects was voluntary and no negative action was taken against those that refused to participate. The respondents were advised to withdraw their participation at any stage of the study without fear or favour.

The Head of Department of Heath in the Free State Province gave permission in writing before the subjects were interviewed.

The nature of the study was thoroughly explained to the subjects and each signed the consent form before participation. The consent form was translated from English to Sesotho language.

The participant information leaflet and consent form was translated into Sesotho language (which is commonly spoken in this area) for the participants' better understanding. Also the interviews were conducted in Sesotho language and recorded. The recording of each interview was fully translated and transcribed in English and was analysed thereafter

Informed consent was obtained from individual participant in private after the participant information leaflet and consent form translated into Sesotho language had been explained to them.

All subjects were 18 years old and above (i.e. above the age of personal consent). They were legally and mentally capable of giving consent.

Lastly, the commencement of the study was subject to the approval of the Research Ethical Committee of Stellenbosch University.

3.20 Participant information leaflet and consent form

The participant information leaflet and consent form are attached as **Appendices B and C.**

CHAPTER FOUR

RESEARCH FINDINGS

A total of 39 pregnant women participated in the focus group discussion in the 4 cluster areas.

4.10 Participants profile

The profile of the focus group participants were as follows;

1. Ages between 18 and 40years.
2. Single with the first pregnancy, but HIV positive and unemployed.
3. Single with the first pregnancy but HIV negative and unemployed.
4. Married with the first pregnancy but HIV positive
5. Married with the first pregnancy but HIV negative
6. Married with more than one pregnancy but HIV positive.
7. Married with more than one pregnancy but HIV negative.
8. Single with more than one pregnancy but HIV positive.
9. Single with more than one pregnancy but HIV negative.
10. Single with the first pregnancy, HIV positive, and employed.
11. Single with more than one pregnancy, HIV positive and employed.

4.20 Major Themes of Findings

The focus group participants expressed enough similar viewpoints which made it possible for thematic generalisations. The findings were organised under eight major themes. These are:

(1) Knowledge about the program.
(2) Perceptions on the concerns about the program.
(3) Perceptions about the readiness or ease of doing HIV test.
(4) Perceptions about the ease of taking ARVs
(5) Perceptions about the relationship between participants and the clinic staff.
(6) Expected reactions from family members if the program advices are followed.
(7) Perceptions on the advantages of the program.
(8) Perceptions about how it feels like to be part of the program.

4.21 Knowledge about the Program

4.21A. Knowledge about how the virus is transmitted from mother to the baby.

Most of the participants knew how the Human Immune Deficiency Virus (HIV) passed from the mother to the child.

Some said it could be transmitted to the baby in the intra-uteri. In the words of one participant:

"*The Virus can be transmitted from the mother to the baby in the womb when the placenta or the womb is injured; or when there is breakage of the water"*

A participant also mentioned that, the transmission can occur during labour:

"*The transmission could occur during delivery when the baby has scratch marks on the body and blood of the mother comes in contact with the wound, or enter the ears or eyes of baby".*

The mothers were aware that breastfeeding as well as mixed feeding after delivery is one way of transmitting the virus from the mother to the baby:

"Yes, the virus is in the breast milk and the baby gets it if the mother is breast feeding and giving water formula milk at the same time"

Refusal to test for HIV during antenatal was mentioned as one way in which the mother transmits the virus to the baby.

"If *the mother did not do the test, she wouldn't know her status and she can transmit the virus to the baby unknowingly".*

4.21B. How the clinic staff tries to prevent transmission.

The focus group participants showed high knowledge of how the health workers try to prevent HIV transmission from mother to babies.

Few participants said the health workers' encouraged pregnant women to attend antenatal clinics and do VCT as a way of preventing the transmission:

"*They(clinic staff) tell us to come and register in the clinic as soon as we know that we are pregnant and in the clinic they will teach us about the disease and also encourage us to do the test"*

One participants mentioned advice on disclosure as a way of preventing the disease transmission to the baby, as she puts it:

"*They (clinic staff) usually advise us to tell our husbands and relatives about our status, and to invite our husbands to the clinic for more lectures, and to also do the test".*

Most of the focus group participants said that the clinic staffs tries to prevent HIV transmission from mother to child by educating them on how to feed the baby, and how to care for the baby and themselves, one of the participants input summarised this as follows:

"*The nurse tells us a lot, they always teach us about good nutrition, and how to breastfeed or how to prepare formula feeds. They also teach us on how to care for ourselves and the baby".*

Some participants said they were advised to do the test for the baby after delivery:

"*They (clinic staff) encouraged us to do test for the baby so that we will know the status".*

Some said the clinic staff, advised them on the use of condoms:

"They (clinic staff) said we should use condom even when we are positive".

Almost half of the participants said the clinic staffs tries to prevent HIV transmission from mother to child by offering the antiretroviral therapy:

"*They (clinic staff) are giving ARVS to those who are positive ".*

One of the participants even said, the clinic staff encourages them to participate in support group:

"They (clinic staff) advised us to join support groups"

4.22. **Perceptions about the Concerns or Disadvantages of the Program**;

The focus group participants discussed their concerns about the program. When discussing their concerns or disadvantages of the program, experiences of other people and anticipated fear of the program (such as resistance to ARVs) based on their knowledge of the program rather than personal experiences affected their opinions in most of the discussions. They were mostly concerned about resistance to ARVs, fear of stopping the treatment after delivery, high number of orphans, depression and suicide as well as family neglecting the baby if the mother dies.

More than half of the focus group participants mentioned resistance as one of their concerns about the program.

"There could be resistance to the ARVs at the time the CD4 count drop to the level that you will need them if you stop the treatment".

Another fear about stopping the treatment after delivery is psychological, as one participant puts it:

"*This medicine is your only hope against the disease and when you are taking it, you feel protected, but if you stop it after delivery, you will loose hope and feel unprotected, and will be very afraid".*

Most of the focus group participants were also concerned about what will become of their children, if they eventually die from the disease. 2 participants argued:

Participant 1: "Who is going to take care of the baby if I die? – no grandmother, no grandfather"

Participant 2: "*Orphans will be neglected if the mother dies. It is better both baby and mother die together, I don't want to die and leave the baby*"

Some participants feel that the program might lead to high number of orphans, if the mothers do not continue the treatment after delivery. According to one participant:

"*The government only want to protect the babies; there will be many orphans when the mothers are dead*"

Few participants have experienced problems in the family because of their status. Almost half of the participants felt that the program can lead to stigma, persecution and violence. Below are responses from the focus group participants:

"There is initial confusion and it is difficult to face the people when you are positive."

"It leads to no more love in the relationship where the man accuses the woman as the cause of the problem, this leads to violence and the male partner will beat the woman".

"It leads to divorce when one is positive"

"When they do not know how HIV is transmitted, there will be stigma and discrimination like not sharing cups, chairs, clothes and bathroom".

"My child is now sick and it is because of this woman".

"The child will be stigmatised if he/she grows up to discover that the mother is HIV positive or died of HIV/AIDS".

"There will be lack of support from your close relatives and family".

Conflict between culture and science were other concerns raised by the participants. Below is how the participants responded:

"The grandmother does not agree that you are not breastfeeding, it is against the culture. According to culture you are suppose to breastfeed the baby"

"The grandmother gives the baby water, when the baby is left in her care"

"The grandmother does not know why the baby is not breastfed. She says I was born before that doctor, and I know much better".

" When a husband dies and you are mourning the sun is not supposed to set on you while you are not at home, if you spend long time in the clinic in winter, this could be a problem".

A working mother raised concerns concerning this program. The response from her own perspective:

"*The working mothers who leaves their babies with a helper or relatives do not know what the helper or relatives feeds the baby with when they are away at w*ork.
Another thing is that the employers should increase the maternity leave , because the private employers for example in the factory gives only six weeks maternity leave and this makes it difficult for the mothers to exclusively breastfeed the baby in the first six months"

4.23 Perceptions on the Readiness or Ease of Doing HIV Test;

More than half of the focus group participants said it was not easy. The fear of being positive was the major concern among those who said it was not easy to do the test. The responses of the participants were influenced by their experiences:

"It *was very scary. I was so afraid because I did not know if I was going to be positive. I went for the counselling because it was compulsory".*

"It was not easy and will never be easy".

"There was initial confusion when the result became positive".

Some participants explained how they were able to overcome the fear of doing the test.

"It became easier to do the test after counselling by the clinic nurse/ sister".

"You must counsel yourself first and make up your mind before going to the clinic for HIV pre-test counselling".

"It is not easy, but you have to do it for the sake of the baby"

4.24 Perceptions on the Ease of Taking the ARVS

At the time of this study, the government have just introduced the dual therapy by adding Zidovudine (AZT) to the Nevirapine (NVP). Before December 2008, it was only NVP. Most clinics were yet to receive stocks of AZT, and so most of the participants who were on the program were to receive peri natal single dose NVP usually taken during labour and as such, they were yet to take the medication.

However, there are two participants who were on Highly Active Antiretroviral Therapy (HAART) which consist of 3 medications regime before they became pregnant, and one participant was on dual therapy.

The responses from those who were on Nevirapine but are yet to take medication because they are not yet in labour were influenced by what they hear from people who took the medication or clinic sisters rather than their personal experience.

"It is not going to be easy especially when you think of resistance in future use when the CD4 count becomes low and this will lead to AIDS".

"You have to take it because of the baby and because'

"I will like to continue the medication after delivery"

Response from one lady, who was already on dual therapy:

"*You can forget, if you did not disclose your status and no body is helping you or supporting you* at home, *to encourage you to take the medication"*

Another response from a participant who is on HAART:

"The side effects are harmful"

4.25 Perceptions on the Relationship between Participants and the Clinic Staff

Majority of the participants were happy with their relationship with the clinic staff. They responded as follow:

"The relationship is good, the sisters are very open they tell you everything and you are free to ask questions"

"The sisters do not discriminate, and we understand when they shout at us when we refuse to do the test"

But few others had bad experiences with the clinic staff. According to the participants in this category:

"Some clinic staff are abusive – using abusive words because of my status. They are hostile"

"The sisters don't give feedback after examining you and the baby in the womb. They always say: see you next time".

4.26. Expected Reactions from Family if the Program Advice was followed

More than half of the focus group participants expected negative reactions from their family members if they followed the program advice. Some of these responses were influenced by cultural and traditional values. For example:

"The grandmothers and the elders will want you to follow culture and will not understand why baby is not breast fed or why baby is not given water or porridge".

The negative attitude of the male partners also influenced their responses.

"*The husband will say I am the man of the house and I paid your dowry. I will not use the condoms and this can make the male partner to be unfaithful and it can lead to divorce".*

"The male partners will refuse to do the HIV test".

"If I am positive, and my husband is negative, he will divorce me"

"The husband usually says, to the woman: '*this is yours and not mine' or 'you brought it into the marriage or relationship'- and they will refuse to do the test".*

But some participants believed that if the family members are counselled and educated about HIV, they will be more supportive.

"If they do not know how HIV is transmitted their will be stigma, like not sharing cup, chair, clothes or bathroom".

They also expected negative reactions from the extended family.

"People will judge you; there will be stigma, and lots of gossiping. They will try to avoid you, but despite this you know how to take your decision by yourself'.

"*They will persecute you that you have brought this disease to the family.*

Very few participants expected love and support from their family members.

"I expect my family members to understand and support."

4.27 Perceptions on the Advantages of the Program

The participants quite agreed that the program has lots of advantages. This response is based on what they had experienced personally.

Most of the participants regard the knowledge gained by participating in the program as one of the advantages. This response is also influenced by personal experiences: This is how they responded:

"*It makes you to know your status, so that you can take care of yourself and the baby and also you are relieved of the stress of not knowing your status"*

"The program gives you information on how to protect yourself and to care for the baby.

"The program encourages you to advise others"

Some of the participants felt that the program prevents the transmission of HIV from mothers to their babies as one of the advantages. Some of the participants expressed their fact as below:

"The program makes your baby to be HIV negative or increases the chance of your baby being HIV negative"

"*It makes you and your partners to know your status in case of future pregnancies"*

Some of the participants also felt that the program reduces the fear of doing the test:

"Before the program, I was so afraid of doing the test, but it became easier after counselling".

One Participant even believed that the program can positively change some cultural beliefs. According to her:

"*The advice of the program can change the culture of our people as they will be able to see things differently*".

4.28 Perceptions on what it is like to be part of the Program;

All the participants were excited to be part of the program; nobody said she is not happy. Their responses:

"I am very excited about the program, because I now know so many things I did not know before and I will advise others about the program"

"It is good because it gives you hope when you are positive and the government has done well by bringing the program"

"I like the Program"

CHAPTER FIVE

DISCUSSION OF THE FINDINGS

5.10 Knowledge about the Program

The participants in each of the focus group discussion session demonstrated substantive knowledge about the PMTCT program. This could be as a result of the information received during the pre and post test counselling session and the health talk session offered by the clinic staff.

This finding compared favourably with other studies. Most women learn about the PMTCT programs from the clinic counsellors.[38]A quantitative study was done in 2004 among a population in the Kampala district of Uganda to establish the knowledge of the population about HIV transmission via MTC. 1491 respondents were interviewed and out of this number 64%were female. Initially, sexual intercourse was most known mode of HIV transmission (97%) while only 16% knew PMTCT as a mode of HIV transmission. But after counselling, this percentage increased to 70%.[39]

In another study conducted in two district hospitals in Kenya, to determine Knowledge, Attitude and Practices (KAP) on prevention of mother to child transmission (PMTCT) of HIV among Mother and Child Health (MCH) clinic attendees before and after implementing an integrated program for prevention of mother to child transmission of HIV. At baseline 330 first antenatal attendees were interviewed at each site before the PMTCT programs were implemented and 800 women from each site were again interviewed using the same study instrument after the program were implemented. According to the authors, there was significant improvement in women's knowledge in ways in which babies can acquire HIV infection and on how to prevent HIV infection in children. For example at baseline level, only 16%of the women were aware that medicine from the hospital could prevent Mother - To - Child – transmission (MTCT) of HIV compared to 34% at follow up ($p<0.000$) at Karatina hospital while in the other Homa bay district hospital 20% of the women of baseline and 58% at follow up ($p<0.000$).[40]

5.20 Perceptions on the Concerns about the Program

The focus group discussants expressed their concerns regarding the program. They were concerned about resistance to ARVs when its use becomes necessary in future and the fear of stopping the ARVs after birth. They were also worried about the idea of saving the baby alone when the parents are going to die, a process that may lead to high number of orphans.

The problems of stigma, discrimination, persecution, domestic violence and even divorce as a result of their status as well as cultural beliefs and traditional values that impede the implementation of the PMTCT program were other concerns perceived by the participants.

The working mothers among the participants were also not happy about the inadequate maternity leaves that are granted to them by their employers as this could hinder the implementation of the PMTCT program. In a research conducted in Tanzania, it was discovered that while the health worker did a wonderful job of convincing the women of the advantages of exclusive breastfeeding, they left the women to their own devices when it come to solving the practical problems of breastfeeding at the same time as holding down a full-time job. It was found that the women had to deal with conditions such as no onsite childcare, lack of expressive or breastfeeding room, and short maternity leaves at most workplaces.[41]

These concerns raised by the participants were similar to those found in other studies.

Studies have shown that the women participating in the PMTCT program oftentimes complains about the hopelessness of saving the babies when the parents are hoping to die as well as some taboos that hinders the implementation of the PMTCT program.[18]
In Mombassa Kenya, 90(31.0%) out of 290 HIV positive women who were included in an intervention study to reduce mother – to – child transmission of HIV, informed their partners of their results. In 3 cases the woman was chased away by her partner, and in 3 cases she reported violence. So, six (6.6%) of the 90 HIV-infected women who were expecting a supportive attitude, experienced violence instead. In the same study, 16% of the respondents reported finding HIV testing useless and were depressed, mainly because HIV has no cure.[42]

Another concern raised by some of the focus group participants is the issue of depression and suicide. Some of them believed that some women could be depressed or commit suicide if they found out that they are HIV positive. This fact was also reported in some other studies. In a multi- country study conducted between 2001 and 2003 to examine community understanding and experience of HIV stigma in 1 rural and 1 urban site each in Ethiopia, Tanzania and Zambia. Data shows that family and community stigma impedes people ability to discuss safer sex with partners, use condoms, disclose HIV status, use PMCTC and VCT services, treat opportunistic infections and provide care. Also the quality of life is additionally compromised as PLWHA most of the times acts on the external stigma they experience leading to self isolation, self depreciation, giving up life aspirations, internalizing guilt and blame and sometimes contemplation of suicide.[43]

5.30. Perception on the Readiness or Ease of Doing HIV Test

With regard to the ease of doing the HIV test, more than half of the participants perceived it as difficult mainly because of the fears of a positive result.

Fear of doing the test because of a positive HIV results has been reported as one of the barriers to participation in PMTCT program.[44, 45, 46]

Also in another study conducted in Mombasa, Kenya, 16.7% of HIV infected women did not see the advantage in knowing their HIV status, mainly because they were now

worried about being sick or dying (68%) and because AIDS could not be cured anyway (35.3%).[42]

Most of the women who said it was not easy to do the HIV test however agreed that it became easier to do the test after they had undergone HIV pre-test counselling. Likewise, in a study that was carried out in Northern Nigeria in 2007, to examine the predictors of readiness for HIV testing among young people. For men and women, knowledge about HIV prevention, knowledge about a source for VCT, discussion about condom use for HIV prevention and perceived risks were found to be strong predictors for the readiness for HIV testing.[47]

5.40. Perceptions about the Ease of Taking ARVs

Most of the participants were yet to take the anti retroviral (ARV) medications, except for 2 participants who were already on HAART. The arguments from those already on HAART were influenced by personal experiences and knowledge gained during the Drug Readiness Classes, while the responses from those who were not on HAART were influenced by what they heard about the ARVS rather than personal experiences.

Most of the participants perceived that it is not going to be easy especially when they think about the possible resistance that might occur when they need the medication in future when the CD4 count drops; some said they would like to continue the medication after delivery.

Disclosure is another important issue mentioned by the participants that will makes it easier to take the medication, as they argued that if no one is helping or supporting the patient as a result of non- disclosure, the patient can forget to take the medication.

The side effect of the medication is also mentioned as an issue that can make it difficult to take the medications.

Some of these factors which the participants perceived to have the potential of hindering the ease of taking the ARV medication during PMTCT had been reported in other studies. A review of various databases to describe the overall prevalence of ARV resistance in developing World was carried out in 2007 focussing on treatment naïve populations, resistance consequences of Prevention of Mother to Child Transmission (PMTCT) drug regimens and the relationship of medication adherence to resistance. This study suggests that NNRTI resistance exist among women taking intra-partum single dose Nevirapine (SD-NVP) to prevent mother to child transmission of HIV, and both the overall prevalence of NNRTI resistance as well as the frequency of mutant virus in the overall viral population decreases with time since single dose Nevirapine prophylaxis was taken.[48]

Also in a cross sectional study to determine important factors that affects antiretroviral drug adherence among HIV/AIDS male and female adult patients attending a teaching and a referral hospital in Kenya, the most common reasons for missing the prescribed

dosing time were being away from home (68.8%), being too busy (58.9%), forgetting (49.0%) having too many medication to take (32.6%) and stigma attached to ARVS (28.9%).[49]

5.50. Perceptions on the Relationship between Participants and the Clinic Staff.

More than half of the focus group participants had a good relationship with their clinic staff. The clinic staff were said to be very open as the patients were free to ask any question and they did not discriminate. Only few of the participants had negative experiences with the clinic staff as one refer to the clinic sisters as abusive and hostile because of their status. Another participant said that the clinic sisters do not give feed back after examining patients.

Other studies reported similar findings. An anthropological research conducted in Quang Ninh province in Vietnam showed that women were satisfied with the services they received from PMTCT program, and they believed that health care staff offered them not only medical care but also social and emotional support. In fact, the author concluded that the health care system is a vital point of support for pregnant women with HIV.[50]

Also in Kingston paediatric and peri-natal HIV/AIDS program in Jamaica, it was reported that nursing intervention improves the comfort level of women and families with accessing health care in the PMTCT program.[51]

Negative attitude of Health workers have also been reported as one the barriers to participation in PMTCT program.[45]

5.60. Expected Reactions from Family if the Program Advice was followed.

Negative reactions were what most of the participants expected from their families if they followed the program recommendations.

The negative reactions expected were those influenced by negative cultural beliefs and traditional values, stigma, discrimination, persecution as well as the negative attitudes of their male partners and extended family members.

Only very few participant expected love and support from their family members.

PMTCT program users from different background have anticipated negative reactions from their family members if they followed the program advice. Lack of male partner support, family and community stigma has been found to be a barrier to participation in PMTCT program in Botswana and Ethiopia.[43, 45]

In rural southern India, a study showed that if a woman was to breastfeed her baby, negative attitudes expected from the partner would include 84% thinking that the mother is harming the baby, 78% thinking she is not a good mother, 74% thinking she is HIV positive and 66% thinking that she has been unfaithful.[52] In the same study although 85%

of the women interviewed expressed their willingness to be tested, most of them were concerned about confidentiality and disclosing HIV sero - positive status because of fear of negative reactions from their husbands, parents and community.

According to a research from Tanzanian the woman is most likely to receive greater support from her partner and family members when VCT is discussed and agreed upon by the couple before the woman is tested, and that men are threatened and are more likely to react negatively to disclosure even if the result is negative when negotiation of attendance had not happened.[53]

In another study, HIV – Seropositive women whose partners attended HIV voluntary counselling and testing (VCT), were three times more likely to use Neviralpine prophylaxis, four times more likely to avoid breast feeding and six times more likely to adhere to infant feeding method selected than those whose partner did not attend.[54]

5.70. Perceptions on the Advantages of the Program

The focus group participants discussed a lot about the advantages and the benefits of the program. The advantages mentioned by the participants include knowledge gained by participating in the program, prevention of mother to child transmission of HIV, the program reduces or allays fear of doing HIV test, it makes you to know your status and that the program has the potential to change the culture and behaviour of the community for the better.

These responses were as described in other studies for example a study in Kenya demonstrated that participation in Prevention- of- Mother – to -Child – Transmission (PMTCT) of HIV services improves knowledge of mother to child transmission of HIV as well as appropriate intervention strategies among the maternal and child Health attendees.[40]

Also in Blantyre, Malawi, in 2004, the majority of 126 women attending antenatal clinic identified HIV testing of pregnant women as potential benefit and necessary for the prevention and potential control of HIV/AIDS. Knowing about one's status instead of being ignorant was the benefit mentioned in most cases by these women.[55] Other suggested benefits by the study participants were; future family planning as an incentive to reduce the number of sexual partners and knowing the cause of the problem in case a child is failing to thrive rather than blame witchcraft

There are other studies which showed that the program actually prevents or reduces Mother-To-Child-Transmission of HIV.[56, 57]

Between august and June 2005, in Abidjan, Cote d' Ivoire, 107 women on HAART and 143 women who received short course ARV for PMTCT were followed. Most of the infants (75%) were breastfed for a median of 5months.[58] Overall, the rate of peripartum HIV transmission was 2.2% (95% confidence interval [CI] 0.3% -4.2%) and the cumulative rate at 12 months was 5.7%% (95% CI 2.5% -9%). The overall probability of

infant death or infection with HIV was 4.3% (95% CI 1.7%-7.0%) at age 4 weeks and 11.7 % (95% CI 7.5%-15.9%) at age12 months.

A study assessed the factors affecting the decision to undergo HIV testing and enrolment in the PMTC program, the role and perceived benefits and experiences of counselling in a PMTCT pilot program in Khayelitsha, Cape Town.[59] Knowing one's HIV status, practising safer sex and access to antiretroviral treatment were some of the benefits listed. Access to antiretroviral treatment, free infant milk formula and support group were listed as benefits of enrolling in the PMTCT program, and counselling was perceived to positively affect physical and mental wellbeing.

There is no doubt that the knowledge gained through the involvement in the PMTC program have the potential to change misconceptions about HIV transmission, and positively influenced the cultural beliefs and traditional values that mitigate against the implementation of the PMTCT program, especially if the family and members of the community are involved in the program.

5.80. Perceptions of What it is like to be Part of the Program

Surprisingly all the participants gave a positive response regarding what they felt to be part of the program. Their reasons for being very happy about the program were: knowing their HIV status, new knowledge gained about how to care for self and baby and also because the program gives those who are HIV positive hope.[39, 40, 41, 54, 56]

CHAPTER SIX

CONCLUSION

Keeping the objectives in mind, this study yielded very interesting findings from which the following conclusions and recommendations are made:

6.10. Summary of Major Findings

The findings were similar to those of other studies in many respects and they are summarised below:

Knowledge about the Program

The focus group participants demonstrated vast knowledge regarding the PMTCT program. Most of them knew how the virus is transmitted from the mother to the child and how this transmission could be prevented. This high level of knowledge among the participants could be attributed to the counselling and health talks sessions offered by clinic staffs.

Concerns about the Program

They also had their perceived concerns of the program. These concerns are resistance to the antiretroviral medications in case of future use, the fear and anxiety associated with stopping the medications after delivery as the medications are perceived to be source of protection and hope, as well as the side effects associated with the medications. Other concerns perceived by the participants are high number of orphans that might result from the program as the mothers are not adequately cared for, compared to the babies. The participants were also concerned about the problems of stigma, persecution, divorce and domestic violence that might occur as a result of their participation in the program. Conflict with cultural beliefs especially with regard to choice of infant feeding practices was also a major concern. The working class mothers are faced with peculiar problem of inadequate maternity leaves that makes it difficult to practice exclusive breastfeeding.

Readiness or Ease of doing HIV Test

Most of the participating mothers said it was not easy to do the HIV test mainly because of the fear of a positive HIV result especially as the disease has no cure to date. Some however said it became easy to do the test after the pre-test counselling session offered by the clinic staffs.

Ease of Taking ARVs

Few participants who were already on HAART said it was not easy to take antiretroviral medications because of harmful side effects.

Expected Reactions from Family Members if the Program Advice was followed

Majority of the participants expected negative reactions from their family members if they followed the program advice. Cultural beliefs and negative attitudes were some of the factors that influenced this response.

Advantages of the Program

The program is perceived to have many advantages ranging from the knowledge gained while participating in the program, knowing one's HIV status and the reduction of the chances of babies contracting the virus. Other benefits of the program include the fact that it reduces the fear of doing the test. Some participants believed that the program's advice can change the culture practices of the people positively.

What it is like to be part of the Program and their Relationship with Clinic Staff

Further more, almost all the participants in the program claimed to be excited being part of the program, and are happy with their relationship with their clinic staffs.

6.20. Recommendations and Policy Implications

This research study has explored the perceptions of antenatal clinic attendees in Qwa-Qwa. Their perceived knowledge, barriers and benefits as regard the PMTCT program have been carefully considered.
These perceptions to a large extent have the potential to negatively or positively affect the implementation of the PMTCT program in Qwa-Qwa community, as well as South Africa nation as a whole.
For PMTCT interventions to be successful, policy makers will need to consider the following recommendations.

6.21. Community HIV/AIDS Education.

There is need for educating the general public about HIV/AIDS. People need to know the modes of transmission, signs and symptoms and how to prevent the spread of the disease. Primary prevention of HIV infection is absolutely important since there is no cure for the disease to date. The most effective way to prevent MTCT of HIV is to ensure that women do not become infected in the first place.
HIV/AIDS education in the community will help to reduce misconceptions about the disease and stigmatization of people infected with the disease.
This process of educating the community about the disease can be achieved by mobilizing the community with the use of carefully developed community-based materials e.g. community posters as well as the use of the media i.e. the electronic (radio & television) and the print media. Multisectoral approaches would be necessary with the

involvement of the Non-Governmental Organisations (NGO), churches, government trained counsellors and facilitators on HIV education and training.

6.22. Prevention of Mother-to-Child Transmission of HIV Campaign in the Community.

It appears the general public lack awareness of the PMTCT program, hence the stigmatization and persecutions of women on the PMTCT program. The community needs to be educated about the program. Prevention of Mother- to Child Transmission (PMTCT) of HIV materials needs to be developed to increase household, community and national awareness of the challenges of PMTCT program. These materials could include leaflets, community posters, community PMTCT workbook and they should be researched-based that incorporates solutions that would break barriers and resistances and at the same time facilitate and motivate for PMTCT program implementation. Also, these materials should be able to promote behaviour change in the community that will enhance PMTCT program uptake.

The electronic and print media can also be very useful in disseminating this information, and multisectoral approach would be needed.

6.23. Community and Family Involvement in PMTCT Program

The involvement of men, as well as other family members in the PMTCT program is important. This will help to increase the general community support and participation. Men support is needed to enable women to disclose safely their HIV test results to partners and to allow couples to provide support to one another. Men and the close relatives' involvement in the PMTCT program will also help to reduce stigma and discrimination and negative attitudes against HIV positive mothers.

Couples counselling as entry point to PMTCT program will go a long way to eliminate most of the barriers to successful PMTCT program. Such couple counselling must have an integrated model which will include routine enquiry about violence, support for safe disclosure of HIV positive status to sexual partners. For PMTCT program to be successful, the gendered social and physical vulnerabilities of women as well as their inherent societal restrictions that affects voluntary counselling and testing (VCT), antenatal care and the choice of infant feeding practices must be addressed.

6.24. PMTCT –Plus

It is always the concern of most mothers participating in the PMTCT program that the program is all about preventing the baby from getting the virus from their mother. Some of the mothers felt that the program did not care for them but only the babies. Some mothers are apprehensive of the fact that antiretroviral medications which serve as their source of hope will be stopped after delivery of the baby.

These concerns will be addressed through the concept of PMTCT-plus. By PMTCT-Plus, there will be ongoing care, support and treatment for the mothers. Their HIV status will be monitored continuously, and opportunistic infection as well as antiretroviral treatment (ART) will be given when it becomes necessary.

Further more, they would be linked with support groups such as People Living with HIV/AIDS (PLWHA), and their access to food support and community resources will be facilitated. In addition, there will be both physical and psycho-social support for the baby, mother and the family.

6.25. Social-cultural Considerations

It is quite clear that some cultural beliefs and practices as well as traditional values especially in African settings act as barriers to uptake and implementation of PMTCT program. Consideration of community and social factors are important for the accessibility and effectiveness of PMTCT interventions.
PMTCT program will be more effective and sustainable if there is integration of carefully developed innovative health education and culturally appropriate interventions that addresses the concerns of negative cultural practices and beliefs but facilitate or encourage the positive traditional values. This will help to address stigma and discriminatory attitudes towards women with HIV/AIDS, and promote informed decision making by all pregnant women especially those who are HIV positive in the areas of infant feeding practices.
These interventions will also help to empower women to negotiate sex and safe sex, and increase their ability to negotiate condom and contraceptive use, as well as increasing their ability to access effective PMTCT programs and Maternal and child Health (MCH) or Reproductive Health Services.

6.26. Adequate Maternity Leave and Work Place Child Care facilities for women (on PMTCT Program).

Inadequate maternity leave is undoubtedly one of the barriers to successful PMTCT program implementation in working mothers. Some employers grant maternity leave as short as 6 weeks. Lack of child care facilities in the work place and working long hours will render exclusive breast feeding impossible.
Strong political will is needed to protect against discriminatory practices in the workplace, to ensure the right to adequate maternity leave with guaranteed income, maternal and child health care during and after delivery and the right to breast feed and care for children in the work place.[60] The government and employers needs to be encouraged to support mandatory adequate maternity leave, anti-discriminatory measures, provision of child care facilities in the work place for nursing mothers especially those who are HIV positive. Appropriate legislation from government is required with support from international organizations such as WHO and ILO.[41]This should serve as a reminder to health care workers of their advocacy role in ensuring the provision of adequate maternity leave. Letters to employers and liaison with interdisciplinary team members such as social workers could be part of this effort.

6.27. Evaluation and Quality Improvement Program for PMTCT Services

There is need for a formal ongoing process by which objective measures are periodically utilized to monitor and evaluate the quality of PMTCT program services (clinical and administrative) provided to patients enrolled in the program.
Needs assessment and quality improvement evaluation of the PMTCT program should be done annually to ascertain the specific needs as well as the overall efficiency and effectiveness of the program, including its structure, processes and outcomes.
This process will help to define and facilitate a systematic approach to identify and pursue opportunities, to improve services and to resolve identified problems. It will also help to modify and promote evidence-based guidelines that will meet the needs of those enrolled in the program.

6.28. Refresher courses for Health Workers that implement PMTCT program,

Successful implementation of PMTCT program also depends on the availability and quality of services rendered by the health care professionals involved in the program. As innovative changes in policy and protocol as well as restructuring of the program is expected from time to time, there is need for a program of ongoing quality professional development for the health care workers involved in the program This will promote capacity building and effective implementation of the program.

6.29. Full Integration of PMTCT program into the District Health System (DHS)

The PMTCT program needs to be integrated into the District Health System (DHS) as part of the "horizontal" delivered package. This will allow decentralised management responsibility, authority and accountability which will give opportunity to this level of health care to be responsible for the control of budget for the provision of PMTCT services in the concerned district.
Integration into the District Health System (DHS) will ensure continuity of care, effective utilization of resources, sustained regular supply of antiretroviral and adjuvant medications as well as effective referral system within and between districts and levels of care.

REFERENCES

1. WHO: Prevention of HIV in infants and young children: Review of evidence and WHO's activities. Geneva: WHO; 31 Jul 2002 [cited 2008 Feb 24]; Available from: http://www.who.int/hiv/pub/mtct/en/

2. Kanabus A, Noble R. Preventing mother-to-child transmission of HIV. West Sussex: Avert.org; 2007. [cited 2008 Feb 26]. Available from: http://www.avert.org/motherchild.htm

3. De Cock KM, GleunFowler M, Mercier E, de Vincenzi I, Saba J, Hoff E, Alnwick DJ, Rogers M, Shafer N. Prevention of mother-to-child HIV transmission in resource poor countries: Translating research into policy and practice. *JAMA.* 2000 Mar; 283(9): 1175-1182.

4. McIntyre J. Maternal health and HIV. *Reproductive Health Matters*. 2005 May; 13(25): 129-135

5. Heywood M. Development update- From Disaster to Development, HIV and AIDS in Southern Africa. *Interfund*. 2004; 5(3)

6. Department of health. National HIV and syphilis antenatal sero-pravalence survey in South Africa- 2005. Pretoria 2006

7. Shisana O, Simbayi L. Nelson Mandela/HSRC Study of HIV/AIDS: South Africa National HIV Prevalence, Behavioral Risks and Mass Media. Household Survey 2002. Cape Town: HSRC Publishers. 2002. p.85-87

8. Questions& Answers II-Selected issues: Prevention & care. Geneva: UNAIDS/WHO, Jun 2005[cited 2008 Feb26]; Available from: http://www.unaids.org/en/knowledgeCentre/Resources/QandA/

9. Duerr A, Hurst S, Kourtis AP, Rutenberg N, Jamieson DJ. Integrating family planning and prevention of mother-to-child HIV transmission in resource-limited settings. *The lancet* 2005 Jul16; 366(9481): 261-263.

10. WHO. Antiretroviral Drugs for treating pregnant women and preventing HIV Infection in Infants. Geneva: 2004 [cited 2008 Feb 26]; Available from: http://www.who.int/reproductive-health/stis/docsdrugsguidelines.pdf

11. Varga C, Brookes H. Preventing Mother-to-Child HIV Transmission among South Africa Adolescents. *Journal of Adolescent Research*, 2008; 23(2): 172-205.

12. Bajunirwe F, Muzoora M. Barriers to the Implementationof Programs for the Prevention of Mother-to- Child Transmission of HIV: a cross-sectional survey in rural and urban Uganda. *AIDS Res Ther.* 2005 Oct. 28; 2:10

13. Sarker M, Sanou A, Snow R, Ganame J. Determinants of HIV Counselling and Testing Participation in a Prevention of Mother-to- Child Transmission program in rural Burkina Faso. *Tropical Medicine & International Health* 2007; 12(12), 1475-1483

14. Buskens I, Jaffe A, Mkhatshwa H. Infant Feeding Practices: realities and mind sets of mothers in South Africa. *AIDS Care*. 2007 Oct; 19(9): 1101-9

15. Mompati K, Luo C, Rollins N, Willumsen J, Kleitjes S, Phegelo M. Evaluation of infant feeding practices in PMTCT and non-PMTCT sites in Botswana. Proceedings of the *XIV International AIDS Conference;* 2002 Jul 7-12; Barcelona, Spain: 14 abstract no. TuPeF5408

16. Bequet L, Tijou A, Becquet R, Ekouevi D, Viho I, Tonwe-Gold B, Kouadio S, Desgrees du Lou A, Dabis F, Leroy V. Two-year follow-up in a PMTCT project: The women's point of view. Ditrame Plus Project, ANRS 1201/1202, Abidjan, Proceedings of the XV *International AIDS Conference;* 2004 Jul 11-16; Bangkok, Thailand.*Int Conf AIDS*. 2004 Jul 11-16; Cote d'Ivoire. 15: abstract no. ThPeB7067

17. Cohen S. PMTCT community challenges: creating caring & supportive environments for HIV-affected families. Proceedings of the XIV *International AIDS Conference; Barcelona, Spain* 2002 Jul 7-12; 14: abstract no. MoPeG4181

18. Kironde S, Kahamele J, Dibibi G, Griffith R, Msaky H, Nzima M. Should we participate? Community perceptions at PMTCT program sites in Hai and Kilombero districts of Tanzania. Proceedings of the XV *International AIDS Conference;* 2004 Jul 11-16; Bangkok, Thailand: abstract no. D11301

19. Osowole OO, Adewole IF, Abokor L, Adesina AO, Sankale JL, Kanki P. Opinion leaders awareness and perceptions of prevention of mother-to-child transmission of HIV services in Ibadan, Nigeria. Proceedings of the XV *International AIDS Conference;* 2004 Jul 11-16; Bangkok, Thailand. 15: abstract no. ThPeD7888.

20. UNAIDS. AIDS Epidemic update. 2007 Dec

21. UNAIDS. Report on the Global AIDS epidemic. 2008 Aug

22. Tiessen, R. NGO Strategies for Gender Mainstreaming in HIV/AIDS Programming. Proceedings of annual meeting of the *International Studies Association*; 2004 Mar 17; Le Centre Sheraton Hotel, Montreal, Quebec, Canada.

23. UNITED NATIONS. Press Release- Secretary-General hails heroic women leading fight in HIV/AIDS epidemic, says their empowerment key to global response in women's

day message [online]. 2004 Mar 1 [cited 2009Aug 5]; Available from: http://www.un.org/News/Press/docs/2004/sgsm9177.doc.htm

24. Feldman R. Maposhere C. Safer sex and reproductive choice: findings from positive women, *Voice and Choices in Zimbabwe*. *Reproductive Health Matters*. 2003 Nov,; 22 (11): pp 162-173

25. Rutenberg N, Kaufman CE, Macintyre K, Brown L, Karim A. Pregnant or Positive: Adolescent Childbearing and HIV Risk in KwaZulu Natal, South Africa. *Reproductive Health Matters.* 2003 Nov; 22(11): pp122-133

26. Willan S. **Women's empowerment** - **Africa's AIDS vaccine**? Paper presented at the Gender Studies Seminar Series, University of Natal: Durban, South Africa. 2002

27. Petchesky RP. From population control to reproductive rights: feminist fault lines. *Reproductive Health Matters.* 1995 Nov; 3 (6): pp 152-161

28. UNDP. Millennium Development Goals. 2000 Sep

29. UNGASS. Declaration of Commitment. 2001 [cited 2009 Aug 5]; Available from: http://www.unaids.org/UNGASS/index.html.

30. Heise L, Elias C. The sexuality connection in reproductive health. *Studies in family planning.* 1995; 40(7):269-282

31. Mane P, Rao Gupta G, Weis E. Effective communication between partners: AIDS and risk reduction for women. *AIDS.* 1994; 8(1): S325-S331

32. Weiss E, Rao Gupta G. Bridging the Gap: Addressing Gender and Sexuality in HIV Prevention. Washington DC: *International Centre for Research on Women*; 1998

33. UNAIDS Inter-Agency Task Team on Gender and HIV/AIDS. HIV/AIDS, Gender and the Prevention of Mother to Child Transmission (PMTCT). 2008 Jul 16 [cited 2009 Aug 5]; Available from: http://www.unfpa.org/hiv/docs/factsheet_transmission.pdf.

34. Kabeer N. The condition and consequences of choice: reflection on the measurement of women's empowerment. Geneva: *UNRISD*;1999: iv,57s- Discussion paper :DP 108

35. De Bruyn M.Reproductive choice and women living HIV/AIDS. Chapel Hill, NC27514,USA: *Ipas*[online] 2002 [cited 2009 Jul 9]; Available from: http://www.Ipas.org/publications

36. Hankins C. Preventing MTCT of HIV in developing countries: recent developments and ethical implications. *Reproductive Health Matters.* 2000 May; 8(11): 87-92

37. Ross L. Qualitative research- data collection and analysis. In: Carter Y, Thomas C, editors. Research Methods in Primary Care, Oxford and New York: Radcliffe Medical Press. 1997; p. 31-37

38. Creek T, Ntumy R, Mazhani L, Galavotti C, Moore J, Smith M, Han G, Shaffer N, Kilmarx PH. Knowledge, attitudes, and practices regarding prevention of mother to child transmission of HIV (PMTCT) among antenatal and postnatal women in Botswana. Proceedings of the *XV International AIDS Conference*; 2004Jul 11-16; Bangkok, Thailand

39. Najjemba R, Wabwire-Mangen F, Muhwezi E, Rutaremwa G, Lwanga JB. Knowledge about Mother to Child HIV Transmission of population of Kampala distict, Uganda. Proceedings of the *XV International AIDS Conference*; 2004Jul 11-16; Bangkok, Thailand

40. Oyieke J, Kalibala S, Mbori-Ngacha DA, Nduati RW, Rutenberg N, Mwai C, Muthami L, Muita J, Gotink M. The Knowledge, Attitude and Practice (KAP), of mother to child transmission of HIV and its prevention before and after counselling for PMTCT in two Kenyan Hospitals.Proceedings of the *XIV International AIDS Conference;* 2002 Jul 7-12; Barcelona, Spain.

41. Milay RS, Keddy B, Stern PN. Demands out of context: Tanzanian women combining exclusive breastfeeding with employment. *Health Care for Women International.* 2004; 25(3): 242-254

42. Gaillard P, Melis R, Mwanyumba F, Claeys P, Muigai E, Mandaliya K, *et al*. Vulnerability of women in an African setting: lessons for mother-to-child HIVtransmission prevention programs. *AIDS*. 2002 Apr; 16(6): 937-939

43. Nyblade LC, Pande R, Banteyerga H, Bond V, Kilonzo G, Mbwambo J, *et al.* Family and community-level stigma impedes HIV prevention and care, and lowers the quality of life for people living with HIV and AIDS. Proceedings of the *XV International AIDS Conference*; 2004Jul 11-16; Bangkok, Thailand

44. Nagadya A, Najjemba R, Mbulaiteye SM, Wabwire-Mangen F, Kakitahi TJ. Challenges and opportunities to implementation of mother-to-child HIV transmission preventive services in rural Uganda. Proceedings of the *XV International AIDS Conference*; 2004 Jul 11-16; Bangkok, Thailand

45. Kebaabetswe PM. Barriers to participation in the prevention of mother-to-child HIV transmission program in Gaborone, Botswana a qualitative approach. *AIDS Care.* 2007 Mar; 19(3): 355-360

46. Mullings A, Johnson N, Harvey K, Alexander G, McDonald D, Williams E, *et al*. HIV seroprevalence, uptake of interventions to reduce mother-to-child transmission and birth outcomes in Greater Kingston, Jamaica. Proceedings of the *XV International AIDS Conference*; 2004 Jul 11-16; Bangkok, Thailand

47. Babalola S, Readines for HIV testing among young people in northen Nigeria: The roles of social norm and perceived stigma. *AIDS and Behaviour*. 2007 Sep; 11(5): 759-769

48. Shekelle P, Maglione M, Geotz MB, Wagner G, Wang Z, Hilton L, *et al*. Antiretroviral (ARV) drug resistance in the developing world. *Evid Rep Technol Assess (Full Rep)*. 2007 Sep; (156): 1-74

49. Talam NC, Gatongi P, Rotich J, Kimaiyo S. Factors Affecting Antiretroviral Dru Adherence Among HIV/AIDS Adult Patients HIV/AIDS Clinic at Moi Teaching and Referal Hospital, Eldoret, Kenya. *East African Journal of Public Health*. 2008 Aug; 5(2): 74-78

50. Hanh N, Rasch V, Chi B, Gammeltoft T. Post-test Counselling and Social Support from Health Staff Caring for HIV-Infected Pregnant Women in Vietnam. *Journal of the Association of Nurses in AIDS care*. 2009; 20(3): 193-202

51. Palmer PM, Anderson-Allen MM, Billings CC, Moore JT, McDonald-Kerr C, Steel-Duncan JC, Christie CD. Nursing interventions in the Kingston Paediatric and Perinatal HIV/AIDS Program in Jamaica. *West Indian Med J*. 2004 Oct; Vol. 53 (5): pp. 327-331

52. Rogers A, Meundi A, Amma A, Rao A Shetty P, Antony J, *et al*. HIV-Related Knowledge, Attitudes, Perceived Benefits, and Risks of HIV Testing Among Pregnant Women in Rural Southern India. *AIDS Patient Care and STD*. 2006; 20(11): 803-811

53. Burke M, Rajabu M, Kippax S, Crawford J. Men's knowledge of prevention of mother to child transmission (PMTCT) in rural Tanzania. Proceedings of *IAS conference*; 2007; Sidney, Australia

54. Msuya SE, Mbizo EM, Hussain A, Uriyo J, Sam NE, Stray-Pederson B. Low male partner participation in antenatal HIV counselling and testing in northern Tanzanian: implication for preventive program. *AIDS Care*. 2008 Jul; 20(6): 700-709

55. Tadesse E, Muula AS. Knowledge and perceptions of antenatal women towards prevention of mother to child transmission in Blantyre, Malawi. *Central African Journal of Medicine*. 2004 Mar-Apr; 50(3-4): 29-32

56. Guay L, Musoke P, Fleming T, *et al*. Intrapartum and neonatal single-dose nevirapine compared with zidovudine for prevention of mother-child transmission of HIV-1 in Kampala, Uganda: HIVNET 012 randomised trial. *Lancet* 1999; 354:795.

57. Connor EM, Sperling RS, Gelder RD, et al. Pediatric AIDS Clinical Trials Group Protocol 076 Study Group. Reduction of maternal-infant transmission of human immunodeficiency type 1 with zidovudine treatment. *N Engl J Med* 1994;331:1173-80

58. Tonwe-Gold B, Ekouevi DK, Viho I, Amani-Bosse C, Toure S, Coffie PA, *et al*. Antiretroviral treatment and prevention of peripartum and postnatal HIV transmission in West Africa: evaluation of a two-tiered approach. *PLos medicin*. 2007 Aug 21; 4(8): pp. e257

59. Magwaza S, Mathews C. Clients' experiences of PMTCT Pilot Program in Cape Town, South Africa. *Antivir Ther*. 2003; 8(Suppl.1)

60. Confederation Internationale des Syndicats Libres/ Internationale des Services Publics. Protection of motherhood, 2000: We are all concerned. Brussels:*Confederation Internationale des Syndicats Libres*, 2000 [cited 2009 Jul 27]; Available from: http://www.infoforhealth.org

APPENDICES

Appendix A.

CLINIC CLUSTERS FOR PROJECT

How the clinics were clustered for the project

CUSTER 1
1. Phuthaditjhaba Clinic
2. Makoane Clinic
3. Bluegum Bosch Clinic
4. Mphatlalatsane Clinic
5. Mahaig Clinic
6. Qholaqhoe Clinic
7. Tebang Clinic

Venue for focus group discussion: Bluegum Bosch Clinic
Date **:** 3rd March 2009

CLUSTER 2
1. Tina Moloi Clinic
2. Eva Mota Clinic
3. Sekamotho Mota Clinic
4. Dinkweng Clinic
5. Thabang Clinic
6. Makeneng Clinic
7. Tshirela Clinic

Venue for discussion: Eva Mota Clinic
Date **:** 4th March 2009

CLUSTER 3
1. Matsieng Clinic
2. Namahadi Clinic
3. Thaba- Bosiu Clinic
4. Marakong Clinic
5. Riverside Clinic
6. Boiketlo Clinic
7. Bolata Clinic

Venue for Discussion: Namahadi Clinic
Date **:** 5th March 2009.

CLUSTER 4
1. Makgalaneng clinic
2. Paballong Clinic
3. Tseki Clinic

4. Monontsha Clinic
5. Sehlajaneng Clinic
6. Nthabiseng Clinic

Venue for focus group discussion: Makgalaneng Clinic

Date **:** 6th March 2009

Other appendices e.g. Letters of research approval from the ethics committee, letter of permission to interview participants from the Free State Dept of Health HOD , Participants information leaflets in English, Participants Information Leaflet in English, are attached